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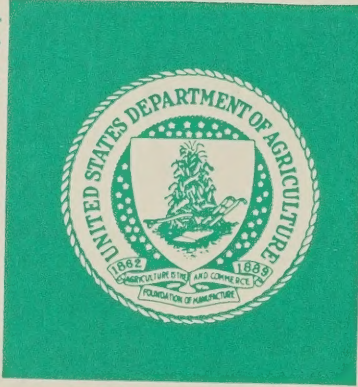
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FEBRUARY 1990

FAMILY CAREGIVING

PREPARED BY BILLIE H. FRAZIER, Ph.D., CFLE**

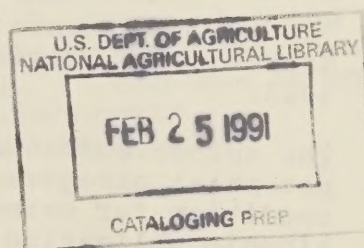
This PATHFINDER has been prepared to help researchers, educators and consumers better understand issues and concerns related to elder caregiving in today's family life.

RESEARCHER/EDUCATOR

"Adult Daughters and Parent Care: A Comparison of One-, Two- and Three-Generation Households," E.M. Brody, M.H. Kleban, C. Hoffman and C.B. Schoonover. Home Health Care Services Quarterly, 9(4):19-45, 1988.

This research compares the effects of parent-care associated with three living arrangements of elderly widowed mothers who are helped by married daughters. Results indicate that daughters whose mothers live separately report the fewest negative effects of caregiving and the mothers are the most cognitively and functionally capable. Daughters in two-generation households provide the most care. These mothers are the oldest and most impaired. Daughters in three-generation households report more negative mental and emotional effects of care. Unique problems of caregiving in such households are discussed.

Received by:
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This PATHFINDER lists significant resources that are judged to be accurate, readable and available. Opinions expressed in the publication do not reflect views of the United States Department of Agriculture.

Adult Day Care-A Practical Guidebook and Manual, Lenore A. Tate and Cynthia M. Brennan. New York, NY: The Haworth Press, 1988. Written for long-term care providers and gerontology students, this publication provides information regarding: (1) history, definition, and concept of adult day care, (2) models of care, (3) scope of activities, and (4) state and national policy development. A manual with forms and reports necessary for daily operations of adult day care program is included. This monograph is written to promote and enhance adult day care as an essential link in long-term care.

"Adult Day Care: Correlates of Its Coping Effects for Families of an Elderly Disabled Member," Shirley L. Zimmerman. Family Relations, 1986, 35(2):305-311, April 1986.

This study demonstrated that the use of adult day care enables family members to better attend to both the disabled person's and the caregiver's needs. It also helps to improve family relationships.

The Burdens of Parent Care: A Critical Evaluation of Recent Findings, Sarah H. Matthews. Journal of Aging Studies, 1988, 2(2):157-166, 1988.

An analysis of the research literature on parent-care reveals that adult children who care for parents are likely to be more disadvantaged with respect to social, physical, and financial resources than the general population. The author feels that the interpretation of research findings is more pessimistic than justified.

"Caregiving within Kinship Systems: Is Affection Really Necessary?" William H. Jarrett. The Gerontologist, 25(1):5-10, 1985.

1981 2-4-11
The author contends that one task of gerontology is to teach potential caregivers that the "affection myth" is not a necessary condition for caregiving. An attitude of positive concern and kinship obligation for older relatives is the motive on which family help needs to rest.

"Care Planning: Case Manager Assessment of Elders' Welfare and Caregivers' Capacity," Karen Seccombe, Rosemary Ryan, and Carol D. Austin. Family Relations, 36(2):171-175, April 1987.

This research examines conditions under which managers in public long-term care programs believe that family and friends can assume responsibility for the long-term care of the elderly. Among five broad dimensions in care plan development, the size of the caregiving responsibility is rated the highest in importance in assessing family responsibility.

"Care-Related Stress: A Comparison of Spouse and Adult-Child Caregivers in Shared and Separate Households," Gary T. Deimling, David M. Bass, Aloen L. Townsend, and Linda S. Noelker. Journal of Aging and Health, 1(1):67-82, February 1989.

The role that relationship and household arrangement have in relation to levels of care-related stress experienced by spouse and adult-child caregivers in shared and separate residences is examined. Results indicate that spouse and adult children in shared households experience similar levels of care-related strain. A comparison of adult children in shared and separate households show that those in shared households have significantly greater activity restriction but less relationship strain.

"Comparing the Depression of Elders in Two Types of Caregiving Arrangements," Ruth E. Dunkle. Family Relations, 34(2):235-240, April 1985.

This paper compares elders living in two types of caregiving households and explores the elder's level of depression in each setting. Results of this study make it clear that even when the elder is cared for by a family member, the caregiving arrangement can be hazardous to the elder's mental health, if exchange is not encouraged. When elders are able to make a noneconomic contribution to the household in both types of caregiving households, they are less likely to be depressed.

"Conflict, Emotion, and Personal Strain Among Family Caregivers," Nancy W. Sheehan and Paul Nuttall. Family Relations, 37(1):92-98, January 1988.

This research examines the influence of interpersonal conflict, affection, and distress caused by dependency and caregiving satisfactions on caregiver strain and negative emotion. Results show that interpersonal conflict in the relationship between the elder and the caregiver is the major factor in predicting both caregiver strain and negative emotion.

"Coping With Caregiving: Denial and Avoidance in Middle Aged Caregivers," Gloria Yvonne Golden. Dissertation Abstracts International, 44/09B:2915, 1982.

This dissertation is concerned with data analysis of cases in which middle-aged persons are coping with health problems of parents, their spouse or themselves. Three coping styles--confrontation, avoidance, and denial--are described. Confronters differ from avoiders and deniers in their ability to express strong negative emotions, such as anger, to themselves and others, and in the skill with which they seek and use social support. Adult children and spouses feel a strong sense of obligation, guilt, resentment or anger, and loss. Adult children fear living to be old-old and acquiring the parent's illness.

"Correlates of Subjective Burden Among Adult Sons and Daughters Caring for Aged Parents," Clifton E. Barber. Journal of Aging Studies, 2(2):133-144, 1988.

This article describes a study of the correlates of subjective burden with the following independent variables: sociodemographic characteristics of the caregiver, cognitive coping strategies, social support, the extent to which adult children prepared for when parents would need care, and aspects of the adult child-elderly parent relationship. Daughters report higher levels of burden than sons. Most measures of social support and attempts to plan and prepare for caregiving are not correlated with feelings of burden. Involvement in caregiving tasks and certain coping strategies are predictive of subjective burden. Gender differences are observed with caregiving tasks and coping strategies.

"Daughters Caring for Mothers: The Experience of Caring and its Implications for Professional Helpers." Jane Lewis and Barbara Meredith. Ageing and Society, 8(1):1-21, 1988.

This study is based on interviews with 41 daughters in Great Britain who care for their mothers on a co-resident basis. It finds that the experience of caring reflects both the commitment to caring and the kinds of problems the carer experiences in dealing with day-to-day situations. Caregivers often experience: loneliness, loss of purpose, difficulty in "picking up the pieces", residual bitterness about behavior of kin, lack of services and financial help, lost opportunities, and anxiety about their own old age.

Duty Bound-Elder Abuse and Family Care, Suzanne K. Steinmetz. Newberry Park, CA: Sage Publications, 1988.

This is an in-depth resource on stress and elder abuse. Chapters include: "The Other Side of The Mountain," "A Historical Overview," "Parenting Your Parent: A Contemporary Analysis of the Problem," "Is It Worth the Effort?: The Impact of Stress on Caregivers and Their Families," and "Patterns, Perceptions and Predictions." A questionnaire on caring for an elderly parent is included in Appendix A.

"Effectiveness of Family Support Group Involvement in Adult Day Care," Peggye Dilworth-Anderson. Family Relations, 36(1):78-81, January 1987.

Support group meetings for adult children who care for older relatives are conducted at two adult day care centers. Eight sessions, 2 hours each, focus on: identifying and addressing problems common to the caregivers, providing information on the aging process, and advising caregivers about available resources. Caregivers benefit more when administrators and staff are involved and also when there is high and consistent attendance of participants. This paper provides guidelines on conducting support groups for caregivers.

Employers and Eldercare: A New Benefit Coming of Age, Bureau of National Affairs, Inc. Washington, DC: The Bureau, 1988. (National Report on Work and Family, Special Report No. 3).

Summarizing major surveys, reports, and studies in the field of corporate eldercare, this report discusses the kinds of assistance employers are providing to employees who are caring for dependent older adults. Case studies of six companies that offer eldercare benefits are included.

The Family Caregiver: Lifeline to the Frail Patient, J. Neil Henderson and Eric Pfeiffer (eds.). Tampa, Fla.: Sun Coast Gerontology Center, University of South Florida Medical Center. 1987.

This manual focuses on ways caregivers can be better trained and supported. It is suggested that "Care of the Caregiver" programs be established to provide: information on the caregiver role, specific illnesses, community resources, and emotional support for the family caregiver. Curricula for family caregiver training and the respite care worker, and prevention and treatment of psychological problems of the caregiver are presented. "Family Caregivers: America's Primary Long-Term Care Resource," Lynn Osterkamp. Aging, (358):2-5, 1988.

The lead article in this special issue on family caregiving emphasizes the primary importance of informal family support and care. The impact of caregiving on lives of caregivers is analyzed. Other relevant articles include: "Helping Caregivers Care," "The Corporate Response to the Working Caregiver," and "Experience Exchange: Treating Stress in Caregiving Families."

"Family Dynamics for Caregivers: An Educational Model," Donna P. Couper and Nancy W. Sheehan. Family Relations, 36(2):181-186, April 1987.

This paper reviews the literature on primary caregivers and describes an educational model on family dynamics for adult children caregivers. Educational programs that focus on the potential stress and types of support required within the family are needed for caregivers.

"Family Help to the Elderly: Perceptions of Sons-in-Law Regarding Parent Care," Morton H. Kleban, Elaine M. Brody, Claire B. Schoonover, and Christine Hoffman. Journal of Marriage and the Family, 51(2):303-312, May 1989.

This article examines consequences of parent care reported by husbands of women who are the principal caregivers of elderly disabled mothers. It compares men's perceptions of caregiving situations with those of wives. Many husbands report personal effects of parent care often cited by principal caregivers. Those sharing households with their mothers-in-law are more likely to report consequences such as interference with social lives, family vacation plans, time with wives and children, and relationships with other relatives. Husbands and wives generally disagree on the extent to which relationships in the family are affected by caregiving but agree about the occurrence of the more objectively apparent lifestyle disruptions.

"Future Outlook, Caregiving and Care-Receiving in the Family Context," William Rakowski and Noreen M. Clark. The Gerontologist, 25(6):618-623, 1985.

The study examines the concept of future time perspective in the context of family giving and receiving of assistance. Data illustrate that difficult caregiving situations can be associated with a less positive future outlook for both family members and impaired elders. Two crucial elements include family communication and the importance of maintaining a future orientation.

"Home Care for Elderly Persons: Linkages Between Formal and Informal Caregivers," Linda S. Noelker and David M. Bass. Journal of Gerontology, 44(2):S63-S70, March 1989.

An investigation of how chronically impaired or frail elders use kin caregivers and formal service providers to meet personal and home health care needs was undertaken. Data indicate that a large portion of households do not use formal services. Caregiver gender and relationship to the care recipient, as well as care-related activity restrictions were important in determining the kind of help provided by service providers and primary caregivers.

"Intergenerational Caregiving: Adult Caregivers and Their Aging Parents," Barbara J. Bowers. Advances in Nursing Science, 9(2):20-31, 1987.

A new theory of intergenerational caregiving is generated. Five conceptually distinct, overlapping categories are identified as: anticipatory caregiving, preventive caregiving, supervisory caregiving, instrumental caregiving, and protective caregiving. Three strategies for protective caregiving are provided.

"Measure of Filial Anxiety Regarding Anticipated Care of Elderly Parents," Victor G. Cicirelli. The Gerontologist, 28(4):478-482, August 1988.

The author develops an instrument to measure filial anxiety that could become a useful research tool in studying the adult child's caregiving behavior. It is possible that moderate levels of filial anxiety can lead to a stronger motivation for caregiving, whereas high levels of anxiety can lead to avoidance of caregiving responsibilities.

A National Dissemination and Replication of the Volunteer Information Provider Program: A Strategy to Reach and Empower Rural Caregivers, Burton P. Halpert. University of Missouri Office Research Administration, University of Missouri-Kansas City, Kansas City, Missouri, 1989.

A Volunteer Information Provider Program (VIPP), created and demonstrated in rural Missouri, was replicated in 20 states, 1986-1988. VIPP was created to empower rural caregivers of frail and impaired elderly through information sharing and knowledge acquisition. As a result of the VIPP, caregivers reported less stress and greater comfort in the caregiving role. Cases of delayed institutionalization were reported in eight states and one case of elder abuse was resolved. In addition, VIPPs experienced heightened self-esteem and greater self-confidence in dealing with personal aging problems.

"Parent Care and Geographically Distant Children," Claire B. Schoonover, Elaine M. Brody, Christine Hoffman and Morton H. Kleban. Research on Aging, 10(4):472-492, 1988.

This research is concerned with geographically distant adult children whose female siblings are primary caregivers for elderly widowed mothers. Female distant siblings are more likely than males to express guilt, strain, and other emotional effects as a result of the mother's situation, in addition to specific intersibling tensions related to the mother's care. This study illuminates the enduring bonds between elderly parents and distant children, in addition to the nature of the problems of these offspring.

"Parent Care as a Normative Family Stress," Elaine M. Brody. The Gerontologist, 25(1):19-29, 1985.

The author asserts that parent care is a normative and stressful experience. A hypothesis is projected that helps to explain the myth that adult children do not take care of their elderly parents.

"Patterns of Parent-Care When Adult Daughters Work and When They Do Not," Elaine M. Brody and Claire B. Schoonover. The Gerontologist, 26(4):372-381, 1986.

This paper approaches the issue of women who participate in the labor force and the effects on parent care. It describes the caregiving patterns evident in a study in which half of the caregiving daughters worked and half did not. Results indicate that workers provide less personal care and cooking than nonworkers. Differences were offset by purchased help.

"Problems and Coping Strategies of Elderly Spouse Caregivers," Amanda S. Barusch. The Gerontologist, 28(5):677-685, 1988.

Interviews are conducted with 89 spouse caregivers to identify problem situations which strain abilities, and coping techniques which prove effective. Findings reveal that caregivers prefer to manage the situation on their own.

"Satisfaction, Communication and Affection in Caregiving: A View From the Elder's Perspective," Ruth J. Parsons, Enid O. Cox, and Priscilla J. Kimboko. Journal of Gerontological Social Work, 13(3/4):9-20, 1989.

Multigenerational caregiving is becoming a prevalent way of caring for moderately to severely impaired elders. Handling the stress created in these arrangements can depend on the relationship between elder and caregiver. This study examines components of such relationships and focuses on caregiving as experienced by the elder receiving care.

"Shared Filial Responsibility: The Family as the Primary Caregiver," Sarah H. Matthews and Tena Tarler Rosner. Journal of Marriage and the Family, 50(1):185-195, February 1988.

How adult siblings organize to meet the needs of their older parents is explored in this research. Five participation styles are identified as: (1) routine, (2) backup, (3) circumscribed, (4) sporadic, and (5) dissociation. In the majority of the research families, there are at least two siblings who are routinely involved with the older parent.

"Sons and Daughters as Caregivers to Older Parents: Differences in Role Performance and Consequences," Amy Horowitz. The Gerontologist, 25(6):612-617, 1985.

This study of adult children who are primary caregivers to an older frail parent indicates that sons tend to become caregivers only in the absence of an available female sibling. They are more likely to rely on the support of their spouses, provide less overall help to their parents, and tend to have less stressful caregiving experiences, independent of their involvement. The author calls for a stronger partnership between formal and family networks to adequately meet the needs of the aged.

"Special Section: The Home Front, Strategies to Assist Patients, Support Providers and Assess Ethics of Home Care," Health Progress, 69(11):38-62, 1988.

Most of this issue is devoted to home care. Special articles include: "Team Approach Enables Frail Elderly to Stay Home," "Collaboration Needed to Bolster Home Care," and "They Are Not Alone: Lending support to Family Care Givers."

"Subjective Burden of Husbands and Wives as Caregivers: A Longitudinal Study," Steven H. Zarit, Pamela A. Todd and Judy M. Zarit. The Gerontologist, 26(3):260-266, 1986.

A two year follow-up study is conducted with a sample of husbands and wives who are caregivers for a spouse with senile dementia. Factors affecting the course of caregiving are identified. Results indicate that subsequent nursing home placement is more strongly associated with caregivers' perceived burden than with severity of dementia. One major implication is that carefully planned interventions may effectively relieve some of the burden experienced by caregivers. Programs that may have considerable impact on subjective burden focus on: coping with everyday problems, providing opportunities for respite, and giving special attention to early interventions.

"Theories of Family Labor as Applied to Gender Differences in Caregiving for Elderly Parents," Nancy J. Finley. Journal of Marriage and the Family, 51(1):79-86, February 1989.

Caregiving to elderly parents is a type of family division of labor. This study investigates four hypotheses of family labor: time-available, socialization/ideological, external-resources, and specialization-of-tasks. Data reveal that these theories of gender differences are inadequate in explaining family caregiving for the elderly. The author addresses the structural nature of the lack of contributions of males to family caregiving and feels that very little behavioral change will occur in caregiving by sons until societal evaluations of men's contributions change.

"Use of Informal In-Home Care by Rural Elders," Janette K. Newhouse and William J. McAuley. Family Relations, 36(4):456-460, October 1987.

This study examines the use of in-home services by older rural people who receive assistance exclusively from informal sources. Suggestions are made regarding how to preserve and enhance the existing informal caregiving structure in rural areas in addition to identifying which elders might be targeted for services.

"Who Nurtures the Nurturer?", Ruth I. Harmelink. Journal of Extension, 25:18-20, Summer 1987.

The author interviews farm women to identify sources of stress and to consider how the Cooperative Extension Service can help meet their needs. Demands of aging parents are identified as one source of stress. A conclusion drawn is that the nurturing role is important, but it needs to be balanced and shared with other family members.

"Worker Views of the Intensity of Affective Expression During the Delivery of Home Care Services for the Elderly," Lenard W. Kaye. Home Health Care Services Quarterly, 7(2):41-53, Summer 1986.

This study provides evidence that even the most basic types of home-delivered services are colored by client expectations for affective/emotional forms of aid. Emotional demands and counseling requests are dominant delivery problems. The provision of home care requires a balance between instrumental and affective orientation.

"Work Status and Parent Care: A Comparison of Four Groups of Women," Elaine M. Brody, Morton H. Kleban, Pauline T. Johnsen, Christine Hoffman and Claire B. Schoonover. The Gerontologist, 27(2):201-208, 1987.

Four daughter caregiving groups are compared: traditional homemakers, those who quit jobs to help their mothers, the "conflicted" workers who reduce their working hours or consider quitting, and those who are gainfully employed. Conflicted workers and women who quit work have the most impaired mothers, and they also experience more disruptions and caregiving strain. Data underline the vulnerability of women to potential conflict between work and parent care.

CONSUMER

"Ageism Is Bad Medicine," Bard Lindeman. 50 Plus, January 1987, 4.

In this investigation, the researcher videotapes doctor-patient visits and concludes that specific ageist assumptions and misconceptions about older people are prevalent. Knowledge of the elderly has not kept pace with the increase in life expectancy. Today, advanced age in the United States can no longer be expected to be associated with frailty.

"The Age-Old Question," Barbara Kallen. Forbes, 138(11):244-246, November 17, 1986.

Caring for elderly parents is never easy. However, there are many more lifestyle options for the elderly today than ever before. This article discusses several options.

"Aging Parents: Helping When Health Fails," Vicki L. Schmall and Lou Isbell. Corvallis, Oregon: Oregon State University, Pacific Northwest Extension Publication 246, July 1984.

This bulletin emphasizes there is no easy or "right" solution to problems people face concerning aging relatives. It is suggested that one needs to look at what is best for all and not to let guilt guide decisionmaking. Families need to build family strengths and to seek help when needed.

"Caring for an Aging Parent: Have I Done All I Can?," Avis Jane Ball. Buffalo, NY: Prometheus Books, 1986.

This book reinforces the concept and practice of intergenerational caregiving. It focuses on the process of what happens to a family when its members become primary caregivers to an increasingly frail grandfather. The experience of this family can be considered a "normative" phase of family life today.

"Caring for Nana," Margaret Opsata. 50 Plus, January 1987, 55-59.

Many women over 50 spend years caring for an aging parent. New options can help them cope. This article discusses support groups, geriatric assessment, and case management. Specific solutions discussed include: assistance with independent living, senior centers, adult day care, respite care, licensed boarding homes, legal and financial advice.

Caring for Your Aging Parents, Robert R. Cadmus. Englewood Cliffs, New Jersey: Prentice-Hall, 1984.

This book is a mixture of inspiration, hard facts, and helpful hints. Contents include: "Tomorrow Is Almost Here," "A Time to Retire," "Money Talks," "Home Sweet Home," "Lifestyles," "Keep 'Em Busy," "Getting Around," "Hope for Health," "The Drugs They Take," "They Are What They Eat," "Homes Away From Home," "Playing It Safe," "The Gift of Grandchildren," "Things of the Spirit," "Three Ways to Cope," and "The Final Challenge."

Coping with Caregiving, Billie H. Frazier. College Park, Maryland: The University of Maryland Cooperative Extension Service Bulletin 326, 1988-89.

This bulletin discusses: Who Are You...the Caregiver; What is Caregiving; Caregiving Stress-Symptoms and Causes; Strategies for Managing Stress; Caregiving At A Distance; and Placement in a Care Facility.

Family Caregivers and Dependent Elderly: Minimizing Stress and Maximizing Independence, D. Springer and T.H. Brubaker. Beverly Hills, CA: Sage Publications, 1984.

This is a resource guide for family caregivers of chronically ill and disabled older adults. It is written for: (a) persons who care for dependent older persons, (b) practitioners who provide service to caregivers, and (c) support groups of caregivers. The emphasis is on reducing the burden of the caregivers' tasks and fostering maximal independence of the elderly.

"Finding Day Care for Your Aging Parent," Cinda Siler. Money, 16(13):199-200, December 1987.

Well-staffed centers are becoming more readily available. This article provides key factors to consider in choosing an adult day care center, deciding whether day care would be more appropriate than a senior citizen center, and determining what financial assistance options exist.

Helping Memory-Impaired Elders: A Guide for Caregivers, Vicki L. Schmall and Marilyn Cleland. Corvallis, Oregon: Oregon State University, Pacific Northwest Extension Publication 314, Reprinted July 1988.

Designed to provide family and professional caregivers with an understanding of dementia in later life and ways to cope more effectively, this publication provides general care and management guidelines. It outlines approaches for handling specific problems; including driving, wandering, money management, catastrophic reactions, hallucinations, eating, incontinence, hiding of items, and communication.

Parentcare: A Commonsense Guide for Adult Children, Lissy Jarvik and Gary Small. New York, NY: Crown Publishers, Inc., 1988.

This book is a practical approach to caring for aging parents. The authors present a six step approach to confronting anger, resentment, and stress that often develop. Constrictions of time, financial worries, social stresses, basics of housing and nutrition, finding proper health care, coping with disability and facing death are identified as the greatest problems that emerge. Workable solutions that are mutually beneficial and draw on the strong bond between parents and children are suggested.

"Stretched to the Limit," Edwin Kiester, Jr. 50 Plus, 28(10):64-70.

This article discusses coping techniques for the "sandwich generation" and focuses on the guilt trap. A self-test on caregiver burnout, and suggestions for help are provided. Visits to Remember: Leader's Guide, Barbara W. Davis. University Park, Pennsylvania: Pennsylvania State University, 1988.

This workshop guide, to be used with filmstrip, can be used by professional or lay educators as they provide guidance to family members and others who provide emotional care as they visit in nursing homes.

Visits to Remember: Handbook for Nursing Home Visitors, Barbara W. Davis. University Park, Pennsylvania: Pennsylvania State University, 1988.

This handbook for family members and others who visit in nursing homes suggests ways to prepare for visits, to stimulate conversation and the five senses of the resident. Suggestions for serving in an advocacy role, when needed, are provided.

C O N T A C T F O R A S S I S T A N C E

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American Society on Aging
833 Market Street
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San Francisco, CA 94130
(415) 543-2617

Children of Aging Parents (CAPS)
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Levittown, PA 19056
(215) 945-6900

Foundation for Hospice and Homecare
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Stanton Park
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(202) 547-7424

The Gerontological Society of America
1275 K. Street, NW
Suite 350
Washington, D.C. 20005-4006
(202) 842-1275

National Hospice Organization
1901 N. Fort Myer Drive
Suite 902
Arlington, VA 22209
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This PATHFINDER resulted from the author's research at the National Agricultural Library while on sabbatical leave from The University of Maryland during the summer and fall of 1989. Using database searches of AGRICOLA, Psycinfo, Social Scisearch, ERIC, Family Resources and Dissertation Abstracts International, relevant references were reviewed and annotated. It is authored by:

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